Your NDIS journey of care starts here

The National Disability Insurance Scheme (NDIS) is a new way to provide support for Australians with a disability, their families and carers.

As a leading service provider, our dedicated team of coordinators are here to support your journey to the NDIS. We’ve got you covered with a wide range of products, equipment, services and supports for your NDIS package, all from our one organisation.

Visit independenceaustralia.com/ndis to learn more about the NDIS and how it affects you.
This Spring 2017 edition of Inform celebrates new beginnings and partnerships, as people move through the national NDIS rollout. As new regions make the transition, we’re seeing a number of people getting their long-awaited ‘fresh starts’ – with new, holistic support packages full of potential.

In our feature story, Rose and her son Aaron give us perspective on living with spina bifida, and join us in welcoming a treatment breakthrough that has the potential to change many lives. Committed to raising awareness of this little-known disability through her work with the Spina Bifida Foundation Victoria, Rose’s perspective shows us just how important partnerships with researchers and medical professionals are.

Independence Australia has always supported the rights of our clients and this is one of the reasons why we’re committed to supporting the NDS ‘Zero Tolerance’ initiatives. Working together with peer-led organisations and various government agencies, we can enable people with disabilities and service providers to prioritise continuous improvement.

We want to hear more from the people we support, and people who support them. If you have a story about your independence, contact us at theteam@iagroup.org.au

Richard Burn
General Manager Community Solutions
What’s on
October — December 2017

**OCTOBER**

4-11 October
National Amputee Awareness Week

6 October
World Smile Day

8-14 October
Mental Health Week

**NOVEMBER**

7 November
Melbourne Cup

14 November
World Diabetes Day

24 November
Independence Australia Daddo Charity Golf Day

**DECEMBER**

1 December
World AIDS Day

3 December
International Day of People with Disability
Earlier in the year, the Prader-Willi Syndrome Association of Australia enjoyed a camp trip in southern Victoria, with some help from Independence Australia.

Our fifth annual ‘Time Out’ camp was held at Camp Cooriemungle near the Great Ocean Road. Although our location promised beautiful coastal weather, Mother Nature had other plans, and provided us with spectacular storms over the weekend.

We had 50 members join us this year, with two volunteers and two carers provided by Independence Australia.

On Saturday, the groups rotated through the activities, which included the giant swing, flying fox and low ropes course. A “Go Orange for Prader-Willi Syndrome” disco was held on Saturday night, with the younger children singing songs with face masks made during the day. There was lots of music, dancing and fun.

Our second day was mostly inside due to the weather. Our ‘Plan B’ included bingo, arts and crafts, and card games. Despite a long day, inside the kids were amazing. Everybody got along so well, and it really demonstrated the reason we hold these camps. The downtime was relaxing and it was wonderful to be able to chat, make new friendships and strengthen existing ones. We were particularly proud of the children when we couldn’t show the scheduled Sunday night movie due to a power outage. Instead, we settled in for a singalong before trying to find our beds in the dark.

On Monday morning the camp staff managed to fit in a few more rounds of activities before saying goodbye for another year.

To find out more about the camp and recreation services we offer, email services@iagroup.org.au
A welcome breakthrough

Photography by Nicole Reed
The medical community recently celebrated a breakthrough in the treatment of spina bifida, where a previously unheard-of treatment is slowly gaining international attention.

This article is republished with permission from the Women's Hospital.

Dr Denise Pedreira, an obstetrician-gynaecologist and foetal medicine specialist at the Albert Einstein Hospital in São Paulo, Brazil, made a special trip to the Women's recently, ahead of her keynote address at the Australian Association of Obstetric and Gynaecological Ultrasound (AAOGU) annual meeting on the Gold Coast.

Dr Pedreira said her research, which had been 14 years in the making, had successfully found a less-invasive method of treating babies with spina bifida in utero, which eliminated the need to open the mother’s abdominal wall to exteriorise the uterus, open it and expose the baby’s spine for operation.

“Through three or more ports (keyholes) we remove the fluid in the womb and replace it with gas so we can do the dissecting and suturing, then we put the fluid back in and the pregnancy continues,” Dr Pedreira said.

“We now have 56 successful cases. So now we really have the numbers to back up what we imagined 14 years ago; that it was doable, safer for the mother and better for the baby.”

Spina bifida (which is Latin for ‘split spine’) occurs when a baby’s spinal cord fails to develop or close properly, leaving the spinal cord and nerves exposed on the surface of the back, with the overlying bone and skin missing.

In most cases, this causes a range of motor and sensory problems for the baby once it is born, including bowel and bladder problems, loss of ability to walk and hydrocephalus – excessive fluid in the brain.

Dr Pedreira said there was growing international interest in the treatment, with a hospital in Israel adopting the practice earlier this year after Dr Pedreira and her team travelled there to teach staff.

“This is becoming mainstream,” she said.
In the face of this breakthrough, we contacted a prominent member of the spina bifida community for comment. Rose Fazio is a board member for the Spina Bifida Foundation of Victoria and her 12-year-old son, Aaron, has spina bifida.

“Raising a child with spina bifida has no rule book, as each child is so unique in their range of disability and the complexity it inflicts on their bodies.”

“Raising a child with spina bifida has no rulebook, as each child is so unique in their range of disability and the complexity it inflicts on their bodies. So many aspects are affected, with particular mention to the brain through hydrocephalus and the Arnold Chiari Malformation, and the kidneys and bladder where inactive nerves render a person incontinent. Physically, the body is left with parts that are not wired to work and paralysis to the limbs. Depending on where the spina bifida is determines which mobility challenges will be encountered for life.

Faced with all these complexities and the lifelong care it requires, individuals with SB and their families welcome any medical research and progression in its care, and the latest in utero surgery is something to follow carefully. This option was not available to me 12 years ago. The procedure itself is still new, and although being practised in the US and parts of Europe by specialised surgeons, carries a great set of benefits and costs that need to be assessed by each family bringing a baby with SB into the world. The proven benefit of reduced
incidence of hydrocephalus is wonderful as it reduces the need for a shunt, but at this stage this is the only significant benefit demonstrated in recent studies highlighted at the World Congress for SB. Other significant benefits that families would be looking for include reduced permanent paralysis and a level of continence of the bowel and bladder. The risks associated with the in utero surgery include premature birth and the risk that the mother may not be able to carry additional pregnancies. I think that as a first-class medical country we should make available this surgery so that a family can have the choice to go ahead with surgery if the benefit can improve the medical outcome. I am also encouraged that the medical world is spending money on research on a disability that is so little-known within the general public and government departments. With awareness and knowledge comes informed doctors, parents and individuals who can make better decisions about the long-term wellbeing and financial support that SB needs.”

To find out more about spina bifida and how you can create awareness, please phone the Spina Bifida Foundation of Victoria on 03 9663 0075.
Robert’s legacy kicks on

The Robert Rose Foundation is a long-time supporter of Independence Australia, and has recently expanded their funding opportunities to people living with spinal cord injuries. This article is republished with permission from the Robert Rose Foundation.

A car accident forty-three years ago left Collingwood and Footscray footballer Robert Rose a quadriplegic, at the tender age of 22. Soon after his death in 1999, the Robert Rose Foundation (RRF) was formed in his honour.

The Foundation was created to provide support for those with spinal cord injuries (SCI) in Victoria, who lack access to other sources of funding. It provides counselling and funding for SCI equipment, modifications, and education programs. Funds raised by the RRF are allocated to those with SCI and their families.

Rehabilitation is not just about physical changes and adjustments when recovering from an injury; it is a process that involves psychological growth as well. It is necessary for someone with a SCI to develop the psychological skills to actively participate socially and protect their mental health. The Foundation provides funding for counselling and psychology services, through Independence Australia’s Psychology Service, to help people adjust to life with a SCI, and the emotional and social changes associated with that.

The RRF provides grant applications to people who have incurred a SCI, including scholarships for those hoping to attain new skills and qualifications. The Foundation also provides community care grants that offer funds for equipment and services to enable more independent living and greater quality of life. Submissions for grants are accepted from individuals and organisations.

Australian singer, entertainer and quadriplegic, Timothy McCallum, received financial support from the RRF. At the age of 18, Timothy became a quadriplegic following a road accident. With help from the Foundation he was able to purchase a new wheelchair.

“I desperately needed a new wheelchair and there was going to be a huge burden both emotionally and monetary-wise. The application process was thorough, and the Foundation’s support and
Robert played 26 games for Collingwood between 1970 and 1973, and nine games for Footscray in 1973, as well as two VFL finals for Collingwood. Robert was also passionate about cricket, playing 19 first class games for Victoria from 1971 to 1974.

The Robert Rose Cup is awarded every year to the winning team in the first AFL round between Collingwood and the Western Bulldogs (formerly Footscray), followed by the Bob Rose-Charlie Sutton Medal, awarded to the best player on ground. The clubs have competed for the Cup since 2000, in recognition of Robert Rose’s contribution to sport, and to raise awareness of disability and SCI.

The contest couldn’t be closer, with the Western Bulldogs evening the score after winning the first match of 2017. The two teams are now level, having won nine games each of the 18 Robert Rose Cup matches since 2000.

For more information on funding and grant applications, please visit the Robert Rose Foundation website at www.robertrosefoundation.com

Robert Rose was the son of famous Collingwood star and coach Bob Rose. Footy was in Robert’s veins and family history, with three uncles also playing for the club. Robert played 26 games for Collingwood between 1970 and 1973, and nine games for Footscray in 1973, as well as two VFL finals for Collingwood. Robert was also passionate about cricket, playing 19 first class games for Victoria from 1971 to 1974.

The Robert Rose Cup is awarded every year to the winning team in the first AFL round between Collingwood and the Western Bulldogs (formerly Footscray), followed by the Bob Rose-Charlie Sutton Medal, awarded to the best player on ground. The clubs have competed for the Cup since 2000, in recognition of Robert Rose’s contribution to sport, and to raise awareness of disability and SCI.

The contest couldn’t be closer, with the Western Bulldogs evening the score after winning the first match of 2017. The two teams are now level, having won nine games each of the 18 Robert Rose Cup matches since 2000.

For more information on funding and grant applications, please visit the Robert Rose Foundation website at www.robertrosefoundation.com

Robert Rose was the son of famous Collingwood star and coach Bob Rose. Footy was in Robert’s veins and family history, with three uncles also playing for the club. Robert played 26 games for Collingwood between 1970 and 1973, and nine games for Footscray in 1973, as well as two VFL finals for Collingwood. Robert was also passionate about cricket, playing 19 first class games for Victoria from 1971 to 1974.

The Robert Rose Cup is awarded every year to the winning team in the first AFL round between Collingwood and the Western Bulldogs (formerly Footscray), followed by the Bob Rose-Charlie Sutton Medal, awarded to the best player on ground. The clubs have competed for the Cup since 2000, in recognition of Robert Rose’s contribution to sport, and to raise awareness of disability and SCI.

The contest couldn’t be closer, with the Western Bulldogs evening the score after winning the first match of 2017. The two teams are now level, having won nine games each of the 18 Robert Rose Cup matches since 2000.

For more information on funding and grant applications, please visit the Robert Rose Foundation website at www.robertrosefoundation.com

Robert Rose was the son of famous Collingwood star and coach Bob Rose. Footy was in Robert’s veins and family history, with three uncles also playing for the club. Robert played 26 games for Collingwood between 1970 and 1973, and nine games for Footscray in 1973, as well as two VFL finals for Collingwood. Robert was also passionate about cricket, playing 19 first class games for Victoria from 1971 to 1974.

The Robert Rose Cup is awarded every year to the winning team in the first AFL round between Collingwood and the Western Bulldogs (formerly Footscray), followed by the Bob Rose-Charlie Sutton Medal, awarded to the best player on ground. The clubs have competed for the Cup since 2000, in recognition of Robert Rose’s contribution to sport, and to raise awareness of disability and SCI.

The contest couldn’t be closer, with the Western Bulldogs evening the score after winning the first match of 2017. The two teams are now level, having won nine games each of the 18 Robert Rose Cup matches since 2000.

For more information on funding and grant applications, please visit the Robert Rose Foundation website at www.robertrosefoundation.com

Robert Rose was the son of famous Collingwood star and coach Bob Rose. Footy was in Robert’s veins and family history, with three uncles also playing for the club. Robert played 26 games for Collingwood between 1970 and 1973, and nine games for Footscray in 1973, as well as two VFL finals for Collingwood. Robert was also passionate about cricket, playing 19 first class games for Victoria from 1971 to 1974.

The Robert Rose Cup is awarded every year to the winning team in the first AFL round between Collingwood and the Western Bulldogs (formerly Footscray), followed by the Bob Rose-Charlie Sutton Medal, awarded to the best player on ground. The clubs have competed for the Cup since 2000, in recognition of Robert Rose’s contribution to sport, and to raise awareness of disability and SCI.

The contest couldn’t be closer, with the Western Bulldogs evening the score after winning the first match of 2017. The two teams are now level, having won nine games each of the 18 Robert Rose Cup matches since 2000.

For more information on funding and grant applications, please visit the Robert Rose Foundation website at www.robertrosefoundation.com
Julia: a story of life and love

Julia is a very special member of the Independence Australia community, joining us in 2015 to access case management services. This year she began her journey from being fiercely independent to requiring more formal supports.

Julia had a rough start to life; being born with an intellectual disability into a challenging family environment meant she was often left to fend for – and defend – herself. To this day, she still deals with the nightmares that this upbringing has caused, with these recollections being vivid even 40 years on. This difficult childhood would cause most to withdraw and become bitter, but not Julia. Throughout all she has experienced, she has been determined to rise above her challenges and live an independent, meaningful life.
Her tenacity has shone through some major turning points in her life, most particularly during the birth of her daughter, Nicola. Nicola was born with a significant disability – so significant that Julia was told she would be lucky if her child lived for a week. However, in true Julia fashion, she refused to listen to their opinions and was determined to give her daughter the best opportunities possible, regardless of how long they had together. Both Nicola and Julia defied all expectations, with Nicola living a life full of love, until her passing at the age of 12.

This same tenacious spirit saw Julia shake off the negative family influences she grew up with and seek a new family – a family who loved and cared for her; the kind of family she deserves. A chance meeting with a taxi driver named Steve formed a fast friendship, with Steve eventually being nominated as Julia’s legal guardian and accepting her into his family with open arms. Together with Steve, Julia felt as if she could take on the world, and with his help she certainly did.

Julia gradually linked up with her community; she became engaged in adult learning, attended weekly bingo, and joined her local church. Her vibrant and loving character meant she has won many hearts, with many of the people involved in her life going above and beyond to give her the best life possible. Every accomplishment has been a cause for celebration and pride, and although she never had a lot, she has always shared her celebrations with others. Julia loves shopping and purchasing gifts for all the special people in her life, paying particular attention to those who have kids that she can spoil.

In 2015 she joined the Independence Australia community to access case management services, and with the assistance of her case manager was given opportunities previously unavailable to her. She was able to engage with her love of English and maths again by attending weekly adult learning classes, and go on a holiday twice; first to Healesville Sanctuary and the second time to Falls Creek to learn to ski. These holidays were particularly important to Julia as she had previously not had many opportunities to go away and make new friends. Finally, since being given unfortunate news about her health, she has been able to tick a number of items off her ‘bucket list’, specifically going to the movies, playing with puppies, and writing a memoir about her life. Her case manager fast became a key individual in her life, allowing her to access many opportunities that would otherwise have been out of reach.

All her life Julia has battled life-threatening illnesses, and although she has always come out on top, she is nearing a new stage of her life where she needs more support. Although this transition is scary for Julia, her history has shown that she will address this time with her trademark tenacity and resilience.

Julia’s biography is a stark reminder of the importance of remaining determined in periods of extreme stress, and being resourceful. Resilience is at the very core of her being, and the progress Julia has made in her life shows this – she is her own protector and advocate, and with the love from the key people in her life she has had the opportunity to flourish as a person.

If anyone living with a disability feels that they may benefit from the assistance of having access to one of Independence Australia’s Case Managers, they can contact Dr Andrew Sinclair on 1300 704 456.
Seasonal Affective Disorder

During winter, the days are shorter and there are fewer hours of sunshine. As the level of sunlight drops our mood can fall as well.

The winter blues or Seasonal Affective Disorder (SAD) is a mental health condition where people who have a normal mood for most of the year experience depressive symptoms in winter. It is estimated that up to 10% of the population experience persistent low mood over the dreary winter months, significantly disrupting their lives.

People experiencing SAD may sleep more than usual, have difficulty waking up, experience poor concentration and have little energy. Personal relationships are affected as well, with people spending less time with family and friends. The condition can also affect the appetite, with people craving carbohydrates, leading some to put on significant weight and further exacerbating their low mood.

Treatments that have been successful in reducing the impact of the condition include light therapy with sunlight or bright lights (best in the morning), antidepressant medication, cognitive-behavioural therapy, ionized-air administration, and carefully timed supplementation of the hormone melatonin.

It is natural during winter to feel withdrawn and in a low mood as a reaction to the persistent cold and dreary weather. Wintery conditions often mean that people have reduced opportunities to interact with the community as the cold keeps many indoors, reluctant to leave their warm cocoons.

If you suspect that SAD is impacting on your mood there are a number of things you can do to pick yourself up:

1. Get as much sunlight as possible, even if it is just sitting at the window on a sunny morning.
2. Seek out warm opportunities for social interaction: invite friends and family over for a movie night, or catch up with friends over a warm hot chocolate.
3. Venture out to the cinema and warm up over a giant bucket of popcorn.

If you feel that you need a bit more support to overcome the winter blues, we recommend that you seek formal and informal supports through your family and your medical team.

To access or find out more about our psychology services, please call 1300 704 456.
TENA Flex
A design breakthrough for wearers and carers

Changing traditional continence products can be a challenge for both wearers and carers alike, whereby many older-style products are cumbersome and not quick or easy to change. The good news is that TENA Flex is making changing easier than ever before. Tenille Taylor, TENA Healthcare Marketing Manager, explains...

Benefits for wearers

- Easy to apply thanks to the unique belted design and absence of excess bulk around the hips.
- Improved skin integrity featuring FeelDry technology to draw urine quickly away from the skin, as well as material that allows the skin to breathe.
- More comfortable to wear with double leg cuff elastics for maximum comfort.

Benefits for carers

- Minimises lifting during changing, which has proven to reduce the risk of back strain.
- Makes changes less intrusive thanks to the belted design.
- The easy belt and tabs makes it simpler to toilet where possible and protection against leakage.
- Extensive range of 12 products across absorbencies and sizes small to extra large. Belt extension also available.

Many people may not realise there have been significant improvements to the form and function of continence products, with modern designs such as TENA Flex delivering significant improvements in changing, skin integrity, odour control and leakage.

“The unique belted design of TENA Flex gives those who are able to self-change the ability to do so – which is just not the case with many other bulky, more traditional continence products. For carers, it makes changing a breeze, and protects their back by reducing the need to lift the wearer onto the pad. For any carers who have experienced back strain, this is simply game-changing.”

With people staying at home longer, who may have more complex care needs, it’s now commonplace for those at home who are both active and mobile, or bed-bound, to need a product that is both easy to change and less cumbersome.

Inform – Spring 2017

Shop online at store.independenceaustralia.com

To request a free sample, call Independence Australia on 1300 788 855 or email customerservice@independenceaustralia.com
Zero Tolerance is a national initiative to promote human rights and tackle the abuse and neglect of people with disability. We asked James Bannister, Manager – Applied Research Projects at National Disability Services, to tell us what Zero Tolerance is all about, and what we can all be doing.

What is the NDS Zero Tolerance initiative?

- Zero Tolerance is NDS’s national approach to promoting human rights and preventing and responding to abuse, neglect, violence and exploitation experienced by people with disability.
- We have been leading Zero Tolerance since 2013. We work with people with disability and families, disability service providers, advocacy organisations, universities and governments to make sure we are listening to people’s real experiences, as well as the academic evidence.

What does Zero Tolerance mean?

- Put simply, Zero Tolerance means that abuse, neglect and violence experienced by people with disability is never okay. It is a commitment to act on anything that makes someone be or feel unsafe, that restricts human rights, or could be done better to empower people with disability.
- Zero Tolerance uses a human rights framework. It sets out clear actions so that the whole organisation – from frontline workers to board members – is focused on the empowerment and safety of people with disability.
Why is NDS doing this work?

• Championing the rights of people with disability is one of our core values. As the peak body for disability services, we think one of our jobs is to make it easier for service providers to work in ways that empower people with disability and support people to be safe.

Abuse and neglect doesn’t happen here...

• The truth is that people with disability can experience abuse, neglect and violence anywhere. People with disability are 1.5 times more likely to experience abuse, neglect, violence and exploitation than people without a disability. (www.who.int/disabilities/violence/en)

• Research tells us that organisations which deny the potential for abuse may actually increase risk for people because they don’t recognise the signs. Organisations need to understand the reasons why abuse happens, what it looks like, and then take steps to reduce the risk of abuse.

How do we introduce Zero Tolerance in our organisation?

• Check out the range of free resources on the NDS website. They include online training programs, workbooks, templates and videos. Use them to check or strengthen your existing policy and training.

• To get started, we recommend that all staff complete the Human Rights and You and the Understanding Abuse programs. Each one is easy to use and takes about 40 minutes to complete on a tablet or computer.

• Follow up by using the video case studies in team meetings and catchups. Discuss what you have seen and how you might do things better as a team. How can you create more empowering lives for people you support, and make it easier for people to speak up?

What does this mean for the NDIS?

• A new national quality and safeguards framework will be introduced as part of the National Disability Insurance Scheme rollout. By using the Zero Tolerance resources, you will not only create positive, empowering cultures, but you will be well placed to meet legislated quality and safeguard requirements both now and under the NDIS.

How long does it take to implement?

• Although the resources are short and easy to use, Zero Tolerance is an ongoing commitment to support the rights of people with disability.

• Zero Tolerance is not just about preventing abuse, it is about empowering people with disability to lead good lives and improve culture. This means the way we listen to people with disability, the way we talk to and about people with disability, and the way we work with our colleagues. There are always things that we can be doing better, and Zero Tolerance will help you to kick-start the conversation and get the ball rolling.

To find out more, contact James Bannister, Manager – Applied Research Projects on 03 8341 4316 or james.bannister@NDS.org.au
As NDIS is rolling out, there is still some uncertainty about the provision of nutrition support to NDIS participants. Nestlé Health Science is dedicated to helping support NDIS participants achieve their nutritional goals, and aiding them to live an independent and full life in the community. This is achieved through the Nestlé Health Science nutrition support program called NCare®, which provides easy and convenient home delivery of nutrition supplies.

The NCare® program has been developed in conjunction with healthcare professionals. The benefits of being registered in the NCare® program include:

- Continuity of care with your nutrition products to help you achieve your nutritional goals for community involvement,
- Access to high-quality nutrition products at the most affordable price,
- Easy and convenient delivery of nutrition products to your home or nominated address.

Nestlé Health Science is committed to providing excellence in nutrition care to healthcare professionals and their patients. Speak to your healthcare professional today about being registered in the NCare® program.

For more information about NCare®, visit www.ncare.net.au or contact the NCare® customer service team on 1800 671 628 (option 3).
As we head towards the end of the year, I hope all is going well with local support groups and their members. I realise that for some groups, maintaining numbers is becoming increasingly difficult with at least two support groups calling it a day. Can I ask that if you find your group in the situation where you are no longer able to meet regularly, that you ensure finances are finalised and any DHHS funding you may have received and not expended is returned to DHHS. If you have equipment that you need to dispose of, it would be of great benefit to Polio Network Victoria if any funds received from the sale of such items could be donated to the Network.

I would also ask that if your group does have to go into recess, you ask your members’ consent to have their contact details provided to Polio Network Victoria if any funds received from the sale of such items could be donated to the Network.

I would also ask that if your group does have to go into recess, you ask your members' consent to have their contact details provided to Polio Network Victoria to ensure everyone is kept up-to-date with any relevant information/news. This information will be kept confidential and not disclosed to any other organisation or source.

The Polio Network Victoria Committee is currently very short on representatives. Gordon McKinnon has had some serious health issues, Joan Tie has had a nasty injury to her arm recently when she was preparing to head to Footscray for the last Committee meeting. Best wishes go to both these valuable members. Fran Henke also made herself available but was unable to continue and I thank her for her contribution. BUT it does mean that we are in urgent need of some additional people on the Network’s committee.

Meetings are held at Independence Australia’s head office at 9 Ashley Street, West Footscray every two months. We commence at 11.00 and finish around 1.30 – 2.00. Lunch is provided and travel costs are reimbursed by IA.

Please consider being part of the Network committee and if you are interested, contact me on email: kyrama@westnet.com.au

Planning for Polio Day 2017 is well underway. This year the theme is “Your Mind Matters” and presenters on the day will highlight the importance of maintaining good mental health as we all deal with other changes in our lives. The venue for Polio Day 2017 is the iconic Bendigo Town Hall and the date is Saturday, October 21st with proceedings commencing at 10.00 and winding up around 3.00.

This day will provide many with the opportunity to come and stay in a beautiful and historic part of Victoria. If you require accommodation over the period, please contact the Bendigo Visitor Information Centre and advise them that you are coming for the Polio Day event.

I do hope as many as possible will be able to attend on the day. Registration and booking information is included in this edition of Inform.

It was recently announced by The Hon. Greg Hunt MP, Minister for Health and Minister for Sport that funding would be provided to Polio Australia for the next three years to assist with Educational sessions for Health Professionals to enhance their knowledge and therefore treatment of Polio survivors nationwide.

Congratulations to all concerned in securing this funding. I know it’s been a long and arduous journey.

The position for Administration Officer for Polio Network Victoria was advertised on line recently. I am hopeful we may soon have some specific support to continue with the work being undertaken.

I wish each and every one of you all the best over the coming months and again urge you to consider becoming a part of the Polio Network Victoria Committee.

Bev Watson
Chair – Polio Network Victoria
A PhD researcher says planning for aged care and ‘successfully ageing’ is not taking into account those living with physical disabilities.

Provisional psychologist Nicola Heath’s comments were made at Polio Day 2017 at Bendigo Town Hall, where she pointed out that while Australia has an ageing demographic and people are living longer, one in five Australians live with a disability.

“The dominant model of successful ageing states that to age well, older adults must be free of disease and disability, maintain high levels of cognitive functioning and remain actively engaged in life.

“According to this model, it is therefore not possible for people with a long-term disability or impairment such as post-polio syndrome to be considered to be ageing successfully.

“This is important because, despite concerns that the current model ignores and encourages the marginalisation of those ageing with disabilities, international governments have increasingly turned to the successful ageing research to help form policy responses that aim to limit the future burden of caring for an ageing population,” Ms Heath said.

The theme of Polio Day 2017 was ‘Your Mind Matters’ Many polio survivors experienced often difficult and distressing periods in their lives, initially with long periods in hospital or within rehabilitation facilities, as well as isolation from families and isolation in the community due to the fear attached to the disease. Many are now experiencing unexpected new symptoms occurring between 15-40 years after the initial infection. Polio survivors are Australia’s largest physical disability group.

Independence Australia’s Manager of Psychology, Dr Andrew Sinclair, told the gathering that chronic pain is a big issue for people living with a physical disability. He noted that many patients are not given the tools they need to deal with pain adequately, and psychology has a lot to offer in relation to chronic pain management.

“We tend to think chronic pain is a fault with the system and we can fix it. While the medications we currently have can mask pain, they can’t fix chronic pain. Psychological approaches are a useful adjunct to medical treatment to manage persistent pain.

“More than 50 per cent of clients referred to my team are referred for assistance to manage chronic pain. After just two four-hour pain management sessions for polio survivors in Geelong, many reported they now had the knowledge to make changes in their lives to enable them to better manage their pain,” Dr Sinclair said.
Polio past & present

PART 2

In the Autumn 2017 edition of *Inform* the first half of 'Polio past and present' was published. In this edition we cover the 'later years' of polio history, from 1937 to the present day.

Polio in Australia and Victoria

1933–2016

**1937:** 1,369 cases in Victoria. Edward Thomas Both developed Australia’s first version of the Iron Lung.

**1938:** Australia recorded its highest incidence of paralytic polio (391 per 100,000 population).

**1950s:** The early 1950s saw Victorian scientist Dr. Percival Bazeley at the University of Pittsburgh in the United States working with Jonas Salk and his team towards the production of a Poliomyelitis vaccine.

North America’s first mass vaccination program was a public health tragedy however, with an improperly inactivated vaccine that resulted in 40,000 cases of polio, leaving 200 children with varying degrees of paralysis and 10 dead. With the success of the Salk vaccine Dr Bazeley returned to Australia to find himself given the task of pioneering the mass production at Commonwealth Serum Laboratory (CSL) of an important new weapon against disease.

**1954:** 569 notifications of polio recorded with 37 associated deaths.

**1956:** Vaccine initially available in Victoria as CSL based in Melbourne.

**1961–62:** Australia’s last polio epidemic.

**1966:** Sabin oral polio vaccine (OPV) introduced in Australia.

**1970s:** Many polio survivors began reporting new problems.

**1972:** Australia’s last case of wild poliovirus.
1987: Polio Network Victoria founded by Edith Hall, acutely aware nothing was being done in Australia for polio survivors. She held a public meeting at Camberwell and to her surprise 125 people turned up. Beth Brodribb who had been working with ParaQuad’s sheltered workshop was asked to help. Within a year 400 survivors were contacted and networks of polio survivors were established to discuss needs and share information.

1988: Australia’s Sir Clem Renouf, as President of Rotary International in 1978 and 1979, led the international campaign to vaccinate every child against polio. This resulted in a partnership between the World Health Organisation (WHO), United Nations Children’s Fund (UNICEF), US Centers for Disease Control and Prevention (CDC) and Rotary International, and launched the Global Polio Eradication Initiative in 1988.

1990: Victoria’s Department of Community Services approved funding to produce the Victorian Polio Network’s first newsletter. Demand from interstate groups saw a seminar held attended by 100 people over concern at the lack of appreciation of polio survivors and needs by medical and paramedical professions.

1991: Post polio clinic run at Bethesda Hospital by Dr Peter Colville, also a polio survivor. A federation of state networks was formed called Polio Australasia, providing resources for new interstate groups.


1998: Polio Services Victoria (PSV) was established by the Victorian Government at St Vincents Hospital to provide ongoing expertise and support for people who had polio. PSV currently consists of a core allied health team including a GP, physiotherapist, orthotist, occupational therapist. Referrals are provided for patients locally.

2007: Health authorities launched a nationwide polio alert and spent the next two weeks tracking down passengers on the same flight as a man infected with polio. The 22-year-old Pakistani man was diagnosed with the first case reported in Australia in 21 years, after returning from a holiday in Pakistan. He was treated in isolation at Box Hill hospital with later support from local polio survivors.

2008: Polio Australia established at a national conference for State Polio Networks.


2016: Life Stage Matters, Australasian/Pacific Conference held in Sydney by Polio Australia, chaired by Dr Stephen de Graaff – Rehabilitation Physician, Director of Pain Services, Epworth Health, Melbourne, acknowledged polio specialist. The conference attracted ‘lived experts’ and polio survivors from USA, Britain, Denmark, Sweden, Italy, Japan, India.
Is your mate feeling blue?

Nothing is more likely to bring a man out in a cold sweat than asking him to talk about his emotions. So how can you spot if your mate’s depressed?

MAN UP!
Our essential health tips for men

All too often, men put off going to the doctor or, worse still, won’t go at all. In fact, studies show that three times more men than women say they haven’t visited a doctor in the last 12 months, while 25% claimed they’d wait as long as possible before getting help with a health problem.

Unfortunately, feeling fine is not the same as being healthy. High blood pressure, blood sugar and cholesterol can silently affect your health, and difficulties urinating may seem small at first, but should be checked out early to avoid potentially serious health problems in the future.

If you or a mate are putting off seeking health advice for fear of finding out about potential prostate issues, diabetes, or heart disease, it’s time to man up! Just like losing weight, changing to a better diet or getting some exercise, it’s about taking responsibility for your own health.
• **Does he seem moody?** Men often disguise bigger personal problems by complaining about life’s little nuisances. If he’s going on and on about the weather or last night’s TV shows, and if you’re worried about him already, it could be a sign that something deeper is wrong. Don’t try to talk in your local pub if other mates are around.

• **Has his routine changed?** Is he missing footy when he used to be on the pitch every Sunday? Has he stopped coming out to the pub or suddenly started going clubbing three times a week? Radical changes in behaviour are often a sign that something’s up.

• **Is he acting strangely?** See how he talks to other people. Does he snap at co-workers? Has he suddenly become shyer or more confident? Is he drinking much more than he normally does, or sleeping less? What’s his appearance like?

Everybody suffers from these symptoms from time to time, so it’s important not to “go to the mattresses”, as the Godfather would say.

However, if you feel these symptoms are starting to affect your mate’s health, it may be time to have a serious conversation. You don’t have to say anything clever or have all the answers, but you do need to listen.

Here are some tips for helping a friend through difficult times:

• **Get him talking.** The biggest hurdle can be getting on to the subject in the first place. Let your mate know you want to help, but do it in a non-confrontational way.

• **Don’t wade in.** Don’t start off by asking him directly what the problem is, whether it’s work or women. You’ll make him defensive.

• **Try a stealth approach instead.** Ask him whether he’s okay. Tell him you’ve been a bit worried about him recently. Ask him if you’re able to lend a hand or if he wants to grab a coffee and talk about it.

• **Go somewhere discreet.** Don’t try to talk in your local pub if other mates are around. And definitely don’t try to talk seriously if you’ve both had too much to drink.

• **Be a listener not a talker.** Ask open-ended questions rather than offering answers. One psychiatrist’s trick is to let the patient do the talking. Ask about how whatever is bothering him started, how the problem has made him feel, or if he’s spoken to anyone else about it.

• **The hardest part is remembering not to offer advice.** Don’t tell your mate what to do, just ask more questions. It’s the talking that’s the therapy, not anything you suggest. If you start lecturing or judging him, he’ll be defensive. And your advice could be wrong.

• **Keep it serious.** It’s tempting to make the situation into a joke because it will help you avoid an awkward conversation. But this isn’t a good time to joke. It might seem like you’re not taking his problems seriously.

• **Make sure you’re okay yourself.** Sharing someone else’s troubles can be stressful. Be sure you’re fit enough for the job before you get involved.

• **Don’t overpromise.** It’s important not to promise solutions. Instead, let him know you’re there to support him and also check if there’s anyone you can contact for him.

---

**Getting help.**

If you’re worried about a loved one’s suicidal feelings, contact your doctor, Lifeline on 13 11 14, or Beyond Blue on 1300 22 4636 for confidential support and advice and referral where appropriate.
Useful information

Polio Australia
03 9016 7678

Polio Services Victoria
03 9288 3900

Post Polio Victoria
0431 702 137

RACV Breakdown Service
131 111

Carers Australia
1800 242 636

Centrelink (Disability)
132 717

Centrelink (Aged)
132 300

Commonwealth Respite and Carelink Centres
1800 052 222

Council on the Ageing (COTA)
03 9654 4443

Disabled Motorists Australia
03 9386 0413

Independent Living Centre
03 9362 6111

TADVIC
03 9853 8655

State-wide Equipment Program (SWEP)
1300 747 937

Polio Network Victoria support groups

Please contact Independence Australia on 1300 704 456 for more details

Ballarat
Wednesdays (bi-monthly)

Bayside (Hampton)
Tuesdays (monthly)

Bendigo
Saturdays (monthly)

Geelong
Mondays (monthly)

Hume
Saturdays (monthly)

Knox-Yarra Ranges
Tuesdays (monthly)

Mornington
Saturdays (monthly)

Shepparton
Tuesdays (quarterly)

South Eastern
Saturdays (monthly)

Traralgon
Wednesdays (monthly)

Warrnambool
Tuesdays (monthly)
We strive to deliver tailored supports that are driven by the person, meaning people with a disability can have as little or as much support as they require. We’re all about ensuring people remain as independent as possible and continue to develop their skills and knowledge.

Our Support Coordination team is highly skilled with many years’ experience working in the disability and social welfare industries.

We partner with you to prioritise understanding the real you, ensuring you gain access to the right specialists and services quickly.

Confidence, when, where and how it matters to you.

Community Solutions. Connecting you with people and services through:

**SPECIALISED MODELS OF SUPPORT**
Personalised, so individuals always have input and direction into their program of supports.

**INTEGRATED FUNDING PROGRAMS**
Reliable, long history with funding agencies TAC, NDIS, DVA, and DHHS.

**QUALITY FRAMEWORK**
Transparency and assurance in service delivery, workforce, and accountability.

1300 704 456
service.enquiry@independenceaustralia.com
Independence Australia is a:
NDIS approved provider
TAC service provider
DHHS service provider

Our services include:
In-home care
Accommodation
Respite care
Psychology and counselling
Case management
Outreach and support
Information
Post polio support
Health care products and equipment